

DESIGNING HEALTH INFORMATION TECHNOLOGY SYSTEMS THAT WORK:
A STUDY OF YOUNG ADULTS WITH CROHN'S DISEASE

A Thesis
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ABSTRACT

In recent years healthcare has experienced a paradigm shift from the conventional Biomedical Model to the Patient-Centered Care Model (PCC Model) (Laird-Fick, Solomon, Jodoin, Dwamena, Alexander, Rawsthorne, Banker, ... Smith, 2011). In this new model, the patient takes a more active role in his or her own healthcare, which necessitates increased patient-doctor communication. Health Information Technology (HIT) can facilitate this information exchange and thus improve the quality of care.

The objectives of this study were to document young adult Crohn's patients' health information management and communication practices and to determine how these practices can inform the design of HIT systems. The formative, qualitative research method of Grounded Theory was used in this study. Findings were analyzed within the theoretical framework of Distributed Situation Awareness and HIT system design recommendations were provided.

BIOGRAPHICAL SKETCH

Erica Bupp holds a B.A. in Industrial Arts and has several years experience working as a design professional. Her passion for human-centered design lead her to pursue a graduate degree in Human-Environment Relations, with a concentration in Human Factors and Ergonomics and a minor in Social Aspects of Information Science.

She is intrigued by human cognition and social behavior, and how they influence and are influenced by the design of objects, environments, and technology. Systems thinking, and in particular studying humans as part of a larger socio-technical system, is of great interest to Erica.

Erica cares deeply about design that creates positive changes in the world. Throughout her professional career and education, she has sought out opportunities to learn about and implement design for social justice, sustainability, diversity, and health. She intends to carry this tradition throughout her life.

In January 2013 she will begin a career as an Interaction Designer, where she will design interactions for the community activities market. This career will allow Erica to create interactive experiences that enable millions of people to improve their social, mental, and physical health through community engagement.

Dedicated to the Crohn's patients of the world.

Your strength inspires me.

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TABLE OF CONTENTS

Biographical Sketch	iii
Dedication	iv
Acknowledgements	v
Table of Contents	vi
List of Figures	viii
Chapter One: Introduction	1
1.1 Introduction	2
1.2 Patient-Centered Healthcare	3
1.3 Young Adults with Crohn's Disease	5
1.4 Crohn's Patients	5
1.5 Young Adult Patients	6
1.6 Young Adults' Health Information Practices	8
1.7 Young Adults' Health Information Challenges	10
Chapter Two: Objective, Methodology, and Theoretical Framework	14
2.1 Study Objectives	15
2.2 Choice of Research Methods	18
2.3 Theoretical Framework	18
Chapter Three: Research Methods	22
2.1 Research Study Design	23
2.2 Sample	24
2.3 Interview Techniques	26
2.4 Visual Methods	28
2.5 Verification	30
2.6 Data Analysis	32
2.7 Reciprocity	35
Chapter Four: Findings and Discussion: Human Agents	38
4.1 Human Agents	39
4.2 Change in Health Status	39
4.3 Illness Management	44
4.4 Change in Practitioner	49
4.5 Domain Knowledge	51
Chapter Five: Findings and Analysis: Transactions	55
5.1 Patient-Practitioner Transactions	56
5.2 Patient-Patient Transactions	61
5.3 Practitioner-Practitioner Transactions	63

Chapter Six: Conclusion	66
6.1 Design Recommendations	67
6.2 Limitations and Future Research	80
Appendices	83
Works Cited	88

LIST OF FIGURES

Figure 3.1	Visualization of Data Analysis Process	34
Figure 6.1	Administrative Tracking Example	75

CHAPTER ONE

Introduction

1.1 Introduction

In recent years healthcare has experienced a paradigm shift from the conventional Biomedical Model to the Patient-Centered Care Model (PCC Model) (Laird-Fick, et al., 2011). In this new model, the patient takes a more central role in his or her own healthcare and works collaboratively with medical practitioners to make healthcare decisions (Lamoure, Stovel, Piamonte, Benbow, Singh, Steenstra, Moore, & Burgess, 2011). In light of the active role the patient has begun to take on, patient-doctor communication is becoming increasingly important.

Health Information Technology (HIT) can facilitate this information exchange and improve the quality of care. HIT has the capability to improve both the quality and quantity of information shared between patients and medical practitioners. As such,

patients serve as one main end user group for HIT systems. Therefore, it is important for HIT system designers to understand how patients use HIT systems (Aldiss, Taylor, Soanes, Maguire, Sage, Kearney, & Gibson, 2011).

1.2 Patient-Centered Healthcare

The shift from the conventional Biomedical Model of healthcare to the Patient-Centered Care Model (PCC Model) has changed the ways in which healthcare practitioners and patients interact (Laird-Fick, et al., 2011). In the Biomedical Model, the goal of the healthcare practitioner is to treat a specific illness with a therapeutic intervention (Engel, 1977). This narrow, pathology-oriented approach neglects to consider the patient's experiences and opinions when selecting treatment plans (Engel, 1977). Rather, the healthcare practitioner holds an authoritative role and makes decisions based upon objective medical data (Engel, 1977, Fredericks, Lapum, Schwind, Beanlands, Romaniuk, & McCay, 2012).

In contrast, the PCC Model allows patients and healthcare practitioners to work collaboratively in making treatment decisions (Lamoure et al., 2011). (Fredericks, et al., 2012, Wolf, Lehman, & Quinlin, 2008). Additionally, in this new model, the practitioner takes on a well-rounded viewpoint to treat the patient, rather than the illness. Lamoure et al. (2011) explain that this paradigm shift “involves talking to patients and family, listening to their desired outcomes, collaborating with allied health team members in order to help facilitate these patient goals, and formulating an individualized care plan.” (p. 2). Furthermore, patients, family, and practitioners are encouraged to share the best information available in order to make informed treatment decisions (Irwin &

Richardson, 2006). The PCC Model has the potential to improve both the quality of medical care and patient health outcomes (Lamoure et al., 2011).

1.2.1 Patient-Centered Care and Health Information Technology

Due to the fact that the PPC Model involves patients and practitioners collaboratively making decisions, the facilitation of information sharing is becoming increasingly important. Health Information Technology (HIT) can help facilitate the move to the PCC model of care. HIT systems are digital health information systems that provide clinical information and communications resources to practitioners and patients (Gustafson, 2007). By unifying health information, such as records; test results; and prescriptions, as well as acting as communication tools between doctors and patients, HIT systems empower patients to become involved in their own healthcare.

Additionally, Donnelly (2005) brings attention to the fact that medical records must be redesigned as this paradigm shift occurs. Donnelly suggests that the conventional format of medical record perpetuates the Biomedical Model of Care, and that the PCC Model requires the adoption of a patient-centered medical record (2005).

As noted above, a patient-centered design prospective will allow HIT systems to become effective patient empowerment. Designers of HIT systems can deliver the most usable and pertinent information to users by understanding their needs, abilities, and communication and information management practices (Aldiss et al., 2011). Due to the fact that all user groups are not identical, it is necessary to examine the unique ways with which each population manages health information, in order to tailor HIT system design to better fit their needs (Osterlund, Dosa, & Arnott, 2005).

1.3 Young Adults with Crohn's Disease

This study will focus on HIT system users consisting of young adults suffering from Crohn's Disease. This specific population was chosen because young adult Crohn's patients have uniquely demanding health-related experiences and health information and communication needs. Additionally, young adult Crohn's patients were of special interest due to the fact that Crohn's disease initially presents most often in adolescence and is often most prevalent in patients under the age of 35 (Husain & Triadafilopoulos, 2004, Wexner & Frattini, 2010).

1.4 Crohn's Patients

There is currently a deficiency in literature related to the health information and communication practices of Crohn's patients (Husain & Triadafilopoulos, 2004). Although research is lacking in this area, the scant existing literature suggests that deeper inquiry into this topic could be of great help to Crohn's patients.

1.4.1 Living with Crohn's

Crohn's Disease patients suffer chronic symptoms, which require continuous medical attention and significantly impact their lives (Husain et al., 2004). Chronic symptoms often include diarrhea, gastrointestinal bleeding, malabsorption of nutrients, abdominal pain, and weight loss (Husain et al., 2004). The continuous medical interventions needed to treat these symptoms include change in diet, oral and intravenous medications, and surgical procedures (Husain et al., 2004). For some patients, the interventions successfully lead to remission (Husain et al., 2004). However, despite the

plethora of treatment options, between 25 and 50 percent of patients relapse annually (Husain et al., 2004). The remission-relapse cycle is unpredictable and vastly impacts many non-medical aspects of patients' lives (Wexner et al. 2010). Wexner et al. (2010) note the dramatic impact that living with Crohn's Disease has on a patient's familial, social, educational, and professional lives.

1.4.2 Patient-Doctor Rapport

Due to the ongoing and cyclical nature of Crohn's, it is essential that doctors build strong rapport with their patients and other practitioners in order to provide satisfactory care (Husain et al., 2004). The importance of patient-doctor rapport is even greater in light of the multidisciplinary approach, involving primary care physicians, gastroenterologists, and surgeons, that is required to treat the Crohn's patient (Husain et al., 2004).

1.5 Young Adult Patients

Research has shown that the population of young adult patients can benefit greatly from appropriately designed HIT systems. Due to the challenges and stage of life of young adults, they often need extra support and are more amenable to technological solutions.

1.5.1 A Transitional Period

Osterlund et al. (2005) note that healthcare during the transitional period from pediatric to adult healthcare is often of suboptimal quality. Patients in this age group and

phase of life tend to be ill-equipped to handle the tasks associated with health management, and do not yet understand their role in their own healthcare.

As pediatric patients transition to adult patients, complex physical, maturation, and developmental changes occur (Lehmann & Kim, 2008). Patients in this stage of life are faced with developing a personal identity, becoming independent of their parents or guardians, developing adult sexuality, and choosing a vocation (Lehmann et al., 2008). During this time patients face a mixture of pediatric and adult concerns and expectations (Lehmann et al., 2008). In turn, patients' relationships to their physicians and parents, as well as their healthcare management responsibilities are redefined (Lehmann et al., 2008). For instance, during this transitional period, young patients will encounter independently discussing sensitive medical issues in a medical setting for the first time (Lehmann et al., 2008).

The emerging responsibility of self-management with regards to one's health entails self-directed participation, surveillance, and self-care (Gray, 1996.) In order to undertake these tasks, patients must develop an emerging self-awareness, the ability to perceive and understand unapparent symptoms, and the ability to compare observed symptoms to those which are known and documented (Giarelli, Bernhardt, & Pyeritz, 2008). New tasks may include tracking physical manifestations of disorder, medical care, behavior, and emotions (Giarelli et al., 2008). Additionally, learning to manage one's health information becomes imperative to successful self-management of health during this period (Giarelli et al., 2008, Osterlund et al., 2005).

Furthermore, the formation of effective health information management practices is especially important for this population for two reasons. First, research has shown that

the habits formed in young adulthood tend to translate to the habits that are embraced throughout the rest of a patient's life (Crutzen, de Noijer, de Vries, Brouwer, Oenema, & Brug, 2011). Second, habits adopted in early life affect a patient's immediate health, which in turn affects their health in later life (Crutzen et al., 2011).

1.5.2 Embracing Technological Solutions

Not only does this population have increased health information demands, but they are also likely to embrace technological healthcare solutions (Lehmann & Kim, 2008, Leung, 2003). Patients in this population have a great facility and comfort with computers, as they grew up using them (Lehmann et al., 2008, Leung, 2003). This makes the automations of medical, behavioral, and history collection not only easier, but also preferable to many patients (Lehmann et al., 2008). Additionally, patients in this population tend to have access to communication devices, such as cell phones or laptops, with which to access HIT systems (Lehmann et al., 2008).

1.6 Young Adults' Health Information Practices

Osterlund et al. have identified a set of major areas involved in the communication and management of health information during the transitional period from childhood to adulthood (2005). These areas include:

- Who is involved in the information management process
- How health information is stored
- The types of information that are stored (Osterlund et al., 2005).

1.6.1 Who Manages the Information?

Research shows that patients, their parents, and their healthcare providers are involved in medical information management practices. In one study, it was specifically noted that the mothers of young adults played a key role in organizing health information (Osterlund et al., 2005). In the same study, young adult patients often mentioned needing the assistance of parents, stating health information managements was often a too confusing and overwhelming task (Osterlund et al., 2005). Although studies (Crutzen et al., 2011) have shown that young patients are capable of being active in managing their health, young people have been more successful in accomplishing smaller, more discrete tasks. In addition to patients and their parents, physicians and other healthcare providers are active in organizing and storing medical information, although many patients and parents noted the fragmented quality of such records (Osterlund et al., 2005).

1.6.2 Health Information Storage

A 2005 study shows that young patients and their parents often stored information in a printed format. Parents stored records in filing cabinets, binders, and folders in their homes (Osterlund et al., 2005). These records were kept chronologically, in order to tell a story or explain the history of the patient's health (Osterlund et al., 2005). To supplement the records, parents and patients also kept diaries, marked calendars, jotted notes, and simply remembered important facts (Osterlund et al., 2005). Although they did not use any specific HIT system to keep track of medical information, parents and patients eagerly supported an online HIT system (Osterlund et al., 2005).

1.6.3 Types of Health Information

Patients are required to organize a wide variety of types and formats of health information. For instance, a 2008 study explains that patients often need to retrieve records from doctor's offices, the hospital, emergency department, and specialists (Lehmann et al., 2008). Additionally, they may need to access auxiliary laboratory and imaging test results (Lehmann et al., 2008). Patients and parents are also responsible for tasks such as scheduling appointments, managing medical bills and insurance paperwork, reviewing educational information, managing prescriptions, and communicating with healthcare providers (Lehmann et al., 2008).

1.7 Young Adults' Health Information Challenges

Due to the transitional nature of young adult patients, and the myriad types of health information they must organize and communicate, they may face several challenges. Some of these issues include communicating a cohesive health history, comprehending privacy and confidentiality issues, staying motivated, and understanding the medical world.

1.7.1 Communicating Health History

Young adult patients often encounter difficulty in communicating a comprehensive health history to providers for several reasons. As noted above, patients are unpracticed in managing their own healthcare. Patients in this age group are also likely be transitioning between healthcare providers, both because they have aged out of

pediatric institutions and as they move away from home for life experiences, such as college.

Osterlund et al. list poor communication between pediatric and adult providers and the expectation of young patients to navigate an adult healthcare system as barriers in a successful transition to adult care (2005). The result of these barriers is that the most unpracticed patients are faced with an exceedingly difficult task—to relay a complex medical history to their adult healthcare providers (Osterlund et al., 2005).

Osterlund et al. note that patients suffering from a chronic illness do not feel that any specific one of their healthcare providers has “the whole story” of their healthcare history (p. 582, 2005). Instead, records of specific issues and time periods are stored across a heterogeneous network of providers, with no central record system or coordinator. This scenario leaves patients and their parents tasked with organizing and distributing medical records. To add to their frustration, patients often feel that it is difficult to retrieve records from their healthcare providers. Oftentimes they feel that their doctor is reluctant to release medical records or charge a fee for copies (Osterlund et al., 2005).

Additionally, patients have expressed frustration with the need to explain their health history numerous times (Osterlund et al., 2005). They feel that healthcare providers ask the same generic questions many times and require patients to fill out forms with overly generalized questions (Osterlund et al., 2005). Patients and parents feel that these questions and forms fail to capture the complexity of the patients’ condition, and are ultimately useless in conveying medical history (Osterlund et al., 2005).

1.7.2 Confidentiality

Patients who are new to managing their own healthcare may be unaware of how the confidentiality of their health information works. For instance, a patient may want to discuss a sensitive issue with their doctor, but feel uncomfortable doing so because they are unsure of whether their concerns will be documented and shared. The young patient may also be unable to articulate their need for privacy or understand how to ask a healthcare provider about confidentiality (Lehmann et al., 2008).

Additionally, when patients reach an age of majority, their parents lose access to their health records (Lehmann et al., 2008). When this occurs the patient and parents may feel frustration for several reasons. First, patients who have become comfortable with their parents organizing their records will now have to either manage this on their own or give consent to allow their parents to access the records. Inversely, patients might not understand what information is accessible or inaccessible to their parents, and therefore not discuss confidential issues with healthcare providers for fear of a parent discovering the record. Finally, many patients in the adolescent to young adult age range will continue to be on their parents' health insurance plans beyond the point of reaching an age of majority. While their records will not be disclosed to their parents, parents will still receive bills for services that may be indicative of confidential activities (Lehmann et al., 2008).

1.7.3 Motivation

Younger patients might not yet understand the consequences of their medical decisions and actions. They are also often used to their parents providing them with

short-term consequences, in order to motivate actions that have long-term effects. For example, a mother might motivate her son to take his medication by creating a medication check off chart. The son might not have yet experienced the physical importance of taking the medicine, but rather knows that he must because his mother tells him it is important. The results of this is that younger patients tend to be less internally motivated to actively participate in healthful behaviors (De Nooijer, Oenema, Klok, Brug, De Vries, & De Vries, 2005).

1.7.4 Understanding the Medical World

A final challenge that young adult patients face lies in understanding how the medical world works. It may be difficult for these patients to understand medical concepts and terminology, or to know how to identify reliable sources of information.

Young patients have expressed a frustration with understanding medical documents because they are not familiar with medical terminology (Osterlund et al., 2005). They might not understand the words or formats used to display information, or how to interpret the information.

Adolescent and young adult patients may also struggle with discerning between reliable and unreliable sources of information. They might not know where to look for information, or believe that any information they read is correct. In turn, they may be exposed to incorrect health information (Lehmann et al., 2008).

CHAPTER TWO

Objectives, Methodology, and Theoretical Framework

2.1 Study Objectives

As noted above, young adult Crohn's patients experience many obstacles in the process of managing and communicating health information. In light of the research described in Chapter 1, the objectives of this research study are as follows:

- Objective 1: Document young adult Crohn's patients' health information management and communication practices.
- Objective 2: Determine how these practices can inform the design of Health Information Technology systems.

2.2 Choice of Research Methods

As noted in the introduction, there is a deficiency of literature documenting the

health information management and communication practices of young adults suffering from Crohn's disease. Due to the lack of literature on this topic, a formative, qualitative approach was employed in this study. The qualitative research method of Grounded Theory methodology guided data collection and analysis. Grounded Theory is a highly systematic process through which theory is inductively derived from empirical data (Drauker, 2007, Eaves, 2001). Because the goal of Grounded Theory is to construct theory from the data itself, it is essential to collect thorough, rich data in order to elicit the accurate and complete development of concepts (Eaves, 2001). In Grounded Theory, rather than being shaped by pre-existing theories, both the research process and products are shaped by the emerging data (Eaves, 2001).

Grounded Theory employs the method of constant comparison, where empirical indicators from the data are compared in order to parse out similarities and differences (Drauker, 2007, Eaves, 2001). Using constant comparison, underlying similarities between empirical indicators are discovered, from which coded concepts are defined (Draukner, 2007). For instance, a researcher interested in the lifestyle of video game enthusiasts may observe that some enthusiast enjoy gaming because it gives them a sense of accomplishment, while others enjoy it because it removes them from reality. In this case, the researcher might compare how these two concepts are similar and different, and begin to explore the reasons behind each form of enjoyment. As further data is collected and analyzed, existing concepts are compared with the new empirical indicators and with each other in order to clarify the definitions of the concepts (Draukner, 2007). In the above gamer example, the researcher might ask informants questions about their reasoning for their type of enjoyment. Subsequently, tentative theories are formulated by

inferring plausible relationships between concepts (Drauckner, 2007). Due to the recursive natures of Grounded Theory, data collect and analysis are conducted simultaneously (Eaves, 2001).

This process is guided by theoretical sampling, the process of data collection that is directed by evolving theory rather than by predetermined characteristics (Glaser & Strauss, 1967, Drauckner, 2007). Using theoretical sampling, populations, events, setting, and processes of interest were sampled (Drauckner, 2007, Bryman, 2008). Theoretical sampling influenced both the selection of informants, as well as the type of data collected.

2.2.1 Roots in Healthcare Research

Grounded Theory methodology has roots in sociological healthcare research. The developers of Grounded Theory, Barney Glaser and Anselm Strauss, served as faculty members in the graduate nursing program at the University of California, San Francisco (Stern, 1985). As nursing faculty members, they imparted their knowledge of Grounded Theory upon their students, who then began a tradition of using Grounded Theory in sociological health research (Stern, 1985). Eaves (2001) notes that early Grounded Theory nursing studies focused on: “the nurse and the dying patient (Quint, 1967), the politics of pain management (Fagerhaugh & Strauss, 1977) ...and the management of chronic illness (Strauss & Corbin, 1988).” Additionally, sociologist Kathy Charmaz has conducted extensive research on chronic illness using Grounded Theory, as well as authored several books on the methodology (Charmaz, 1983, 1990, 2005). HIT is

becoming an inherent aspect of the healthcare experience, thus the findings of this study are complementary to this existing body of research.

2.3 Theoretical Framework

As noted above, the young adult Crohn's patient's health information management and communication practices involve numerous healthcare practitioners, information in many formats, and unpredictable changes through time. In light of these aspects, the Distributed Situation Awareness Model was chosen as the theoretical framework with which to analyze findings of the study.

2.3.1 Situation Awareness

Situation Awareness (SA) is defined as state of mind where a person has perceived the elements of the environment within a volume of time and space, has comprehended their meaning, and is able to project their status into the near future (Endsley, 1995). This awareness is defined in terms of the information that is relevant to a specific task or goal (Endsley, Bolté, & Jones, 2003). Therefore, SA entails having an awareness of what is happening, often referred to as a *mental model*, and using that knowledge to make decisions and work towards a certain goal (Endsley et al., 2003). SA grew out of the military aviation field, and has been applied to many decision-critical domains such as power plant operations, dispatching, and medicine (Endsley et al., 2003).

Endsley breaks down the process of reaching a state of SA into a three-step model: 1) perception of the elements in the environment, 2) comprehension of the current

situation, and 3) projection of future status (Endsley et al., 2003). The first step entails perceiving relevant attributes and dynamics of the current situation (Endsley et al., 2003). In this step a person uses all available information sources, including electronic and printed information, the physical environment, and verbal and non-verbal communication with others (Endsley et al., 2003). The second step involves understanding what the information one has perceived means in relation to the task at hand (Endsley et al., 2003). In this step a person must prioritize and synthesize many pieces of information, and compare that information to one's goals (Endsley et al., 2003). In level three, the person uses the awareness gained from levels one and two, combined with his or her domain knowledge (known as a *schema*) in order to predict the future status of elements in the environment (Endsley et al., 2003).

In addition to Endsley's three-step model, Smith and Hancock's perceptual cycle model offers a more dynamic analysis of the process of reaching SA (Salmon, Stanton, Walker, Baber, Jenkins, McMaster, & Young, 2010). Smith and Hancock suggest a "continuous cycle of SA acquisition and maintenance, including both the process (the continuous sampling of the environment) and the product (the continually updated schema) of SA." (Salmon et al., 2010, p. 306).

2.3.2 Distributed Situation Awareness

Due to the fact that people often work in collaborative environments, rather than in isolation, it is advantageous to examine SA in a wider context (Salmon et al., 2010). Distributed Situation Awareness (DSA) describes a state of awareness reached by a joint cognitive system, comprised of both human and non-human agents (the artifacts people

use) (Salmon et al., 2010). This team-oriented approach focuses on the interactions between agents that are essential to reaching a common goal (Salmon et al., 2010). While it is not essential that all agents have identical goals, DSA implies that agents may have different yet potentially compatible goals (Salmon et al., 2010).

In DSA the unit of analysis is shifted from a single person, to the system as a whole (Salmon et al., 2010). While each agent has a different mental model of the same situation, his or her awareness may overlap with, be compatible with, or complement other agents' awareness (Salmon et al., 2010). Each agent's mental model is shaped by the information perceived, as well as his or her internally held schema. No one agent holds the overall DSA, rather it is distributed among agents and artifacts in the system (Salmon et al., 2010).

Furthermore, each agent in the system does not need to know everything. An agent requires only the awareness that is needed in order to reach his or her specific goal, and to remain conscious of what teammates know and need to know (Salmon et al., 2010). In an especially highly distributed system, agents only need to be aware of the information needs of the team members they are working with most closely (Salmon et al., 2010).

In DSA each agent in the system contributes to the development and maintenance of the other agents' awareness (Stanton, Stewart, Harris, Houghton, Baber, McMaster, Salmon, Hoyle, Walker, Young, Linsell, Dymott, & Green, 2009). In the case that an agent is lacking in awareness, his or her awareness can be enhanced through interaction with another agent in the system (Salmon et al., 2010). In this way, interactions are

essential to maintaining both the individual awareness of each agent and the DSA of the system (Salmon et al., 2010).

Information exchanges, sometimes referred to as *transactions*, are an essential aspect of DSA (Salmon et al., 2010). Transactions can take place in many formats, for instance information can be exchanged through a computer system, written report, conversation, or non-verbal behavior (Salmon et al., 2010).

2.3.3 DSA in Complex Socio-Technical Systems

The DSA approach can help understand technology-mediated transactions in systems (Stanton et al., 2009). Hollnagel (1993) suggests that the technical aspects of a system are, in fact, part of the joint cognitive system. Stanton et al. support this assertion by explaining that both human and non-human agents have some level of awareness in that they each hold contextually relevant information (Stanton et al., 2009). Additionally, Salmon et al. (2008) emphasize the importance that artifacts, including technological systems, have in maintaining DSA. Artifacts help a system maintain DSA by holding information, facilitating transactions, and providing new information (Salmon et al., 2010). In this way, DSA accounts for human agents, non-human artifacts, and the way they interact with each other. Therefore, the DSA approach can provide an excellent theoretical framework for understanding complex socio-technical systems, such as the network of healthcare providers, Crohn's patients, and the artifacts they use.

CHAPTER THREE

Research Methods

3.1 Research Study Design

A Grounded Theory study was undertaken. A cohort of informants consisting of ten young adults with Crohn's disease was recruited. Each informant was informed of the goals and implications of the study and asked to signed an informed consent form (see Appendix A for full informed consent form).

First, each informant gathered images documenting his or her health information management experiences. Upon completion of the image-gathering exercise, each informant participated in an approximately one-hour long, open-ended interview. During the interview, a photo-elicitation technique was employed, whereby the images collected by the participant were used to incite and support conversation (Bryman, 2008). Interviews were audio recorded, transcribed, and analyzed. As the process was repeated

for each participant, the results of earlier data collection and analysis informed the reformulation of interview guidelines and themes of analysis. In addition, approximately one-half-hour long follow-up interviews were conducted with select informants.

3.2 Sample

As noted in Chapter 1, this study focused on the population of HIT system users consisting of young adults suffering from Crohn's Disease due to their especially demanding health-related experiences and health information and communication needs.

3.2.1 Informants

Informants included ten Crohn's patients, ages 18 – 29, including six females and four males. Every informant was either a working professional or currently enrolled as a university student.

3.2.2 Recruitment Methods

Informants were recruited in four ways. First, informants were recruited through the Crohn's and Colitis Affiliation at Cornell University. The faculty advisor was contacted and agreed to send a recruiting email to group members. Personal acquaintances of the primary investigator were also recruited via email. Finally, snowball sampling was used to recruit informants; at the end of each interview, informants were asked to recommend friends or family members who might be interested in participating in the study.

3.2.3 Theoretical Sampling

In line with Grounded Theory, the method of Theoretical Sampling was used; The sample was not intended to be representative of all patients, but rather was used to gain a deeper understanding of specific theoretical lines of inquiry (Glaser & Strauss, 1967). Using this approach, saturation on certain topics of interest was reached with the data collected from a relatively small group of informants. Keeping with Theoretical Sampling, initial sampling decisions were made based upon the perspective of interest and guided by the research objectives.

3.2.4 Sampling Bias

In addition to accurately conveying the young adult Crohn's patient's perspective, the importance of including various types of patients within the cohort was noted. Initially, recruitment was only carried out through the Crohn's and Colitis Affiliation at Cornell University. However, it was soon discovered that Cornell students tended to be incredibly organized and responsible, which may not be representative of the typical young adult patient. In response to this issue, recruitment was expanded to include patients with various backgrounds. This expansion included patients from other universities, as well as young professionals.

While undertaking recruitment a number of *non-compliant* patients (patients who do not adhere to medical advice) were referred to the researcher. These patients were contacted with the objective of enriching the study, due to the fact that non-compliant patients may have vastly different health information management practices. Unfortunately, none of the non-compliant patients followed through with participating in

the study. Therefore, it is important to note that sampling bias was present, in that compliant patients were more likely to participate.

3.3 Interview Techniques

Interviews served as the main method of data collection. Thirteen interviews were conducted, which consisted of ten initial one-hour-long interviews and three half-hour-long follow up interviews. While an interview outline was used to guide the interview, the interviews remained open-ended in order to discover themes that had not previously been explored. As the themes were discovered, they were explored with increasing depth. The initial interview outline used is included in Appendix B.

3.3.1 Point of View

As noted by Becker (1956) and Morrissey (1970), interviewee personality and attitude can greatly affect the nature of the interview. For instance, some informants may exhibit an *ideal* viewpoint, while others will express a *cynical* point of view. Although each person usually conveys a mix of these two attitudes, it is important for the researcher to help keep a balance (Becker, 1956). In order to maintain a balance, interview questions were raised in different manners and a flexible interviewing style was employed (Becker, 1956). This balance was difficult to maintain, considering the emotionally charged nature of the interview topic. Additionally, there was a desire to empathize with interviewees, and convey an understanding of their struggles, in order to build rapport. However, it was important for empathy not to be interpreted as encouragement to portray a negative or defenseless attitude. In order to stave off this

issue, questions answered in a negative tone were followed by questions concerning neutral or positive topical areas.

3.3.2 Transcription

Bryman notes that it is essential to audio-record and transcribe interviews, in order to fully capture information while focusing attention on interviewing (2008). All interviews were audio-recorded using Audacity software, a free audio recording and editing software that is available at audacity.sourceforge.net. Phone interviews were conducted over speakerphone in order to carry out audio recording. Transcription took place following each interview. Interview recordings were slowed to 70-80% and repeated two to three times as they were transcribed.

Although transcription took place after each interview, shorthand notes were taken during interviews. These notes were taken in order to guide the interview and monitor follow up questions. Additionally, notes concerning verbal cues were written as transcription of the recorded interview took place. As Portelli notes, it is important to remember that "oral sources are oral sources" and therefore nuances of oral communication may be lost during transcription (1981). Notes such as "long pause," "sadly," and "excitedly" were recorded in the transcript to account for this deficiency.

3.3.3 Assisting in the Formulation of Answers

Initially, a number of interview questions were difficult for informants to answer. The questions were not difficult in that they pried for personal information, but rather because they concerned processes that the interviewees usually completed

subconsciously. In these cases, time was given to interviewees to construct a thought before speaking (although this often entailed an “uncomfortable silence”), detail was pursued by asking clarifying questions, questions were asked from several angles, and the reason for asking questions was explained beforehand (Morrissey, 1970). These techniques gave the informants a larger toolset to work with when attempting to answer difficult questions.

3.3.4 Location

Interviews were conducted in a small interview room (MVR 4202) in Martha van Rensselaer Hall at Cornell University, as well as by telephone. Morrissey notes that location is as an important aspect of interviewing (1970). Originally, it was desired to conduct *contextual* interviews in the patients’ homes; the primary place where they organize their health information. However, due to the constraints of the study it was unfeasible to do so. While the interview room was comfortable and had recently been renovated, it removed the informants from the context where they complete the tasks being discussed. In order to ameliorate this issue, visual methods were used to better understand contextual issues.

3.4 Visual Methods

The visual method of *photo-elicitation* was used to enhance the quality of data collection. Photo-elicitation is a technique where photographs taken by informants are referenced during an interview in order to incite and support conversation (Bryman, 2008). Before the initial interviews, informants were asked to gather 15-20 images related

to health information management. Although they were given the latitude to decide what type of images they include, suggestions were provided to get them started.

3.4.1 Benefits of Photo-Elicitation

In addition to providing context, photo-elicitation enhanced the interviews by grounding the researcher's interview questions, allowing interviewees to engage differently with familiar subjects, stimulating interviewees' memories, and creating a more balanced account of events (Bryman, 2008). As suggested by Bryman, the researcher asked interviewees to point out what was important about photographs used during photo-elicitation (2008). Using photo-elicitation proved to be an invaluable supplement; as an informant grappled to explain a process, they often pointed to images to support their statements or help themselves form thoughts. It was also useful to the interviewer to ask questions about photographs when conversation slowed.

3.4.2 Curation of Photos

The informants were asked to collect the images themselves, rather than the researcher, for several reasons. As Harper explained, visual data is both objective and constructed (2005). It is objective in that it captures a scene in a technical way. However, it is constructed in that the person taking the photo has a certain vantage point, chooses what to include in each photo, and chooses the film and camera settings (Harper, 2005). Further, when a collection of images is combined to create a photo essay, a narrative is constructed (Harper, 2005). Because the informants constructed the sets of images,

additional understanding of how the informants viewed their process, what struggles they felt were most salient, and what was important to them, became evident.

3.4.3 Confidentiality

Giving informants the power to decide which images to share also enhanced the sense of privacy they felt. Due to the fact that health information is a sensitive topic, different informants felt comfortable sharing different levels of information. By allowing them to curate a set of images, they felt assured that they were only sharing to a level they felt comfortable with. Additionally, informants were encouraged to censor private information from images, as well as given directions and software with which to edit their images.

While this system was beneficial in enhancing informant privacy, it is important to consider how having participants curate the collection of images relates to Goffman's dramaturgical perspective. With this perspective in mind, the fact that a systematic representation of events and artifacts was not presented was taken into consideration (Hill, 1993). Rather, the set of images may have been created in a way that frames or creates a preservation of self (Hill, 1993). For instance, a participant may be embarrassed about how disorganized his or her records were, and therefore organized them into a neat stack before photographing them, or avoided photographing them altogether.

3.5 Verification

Verification was conducted throughout the research process in order to assure that data was properly understood and interpreted. Because information presented by

informants may have multiple meanings, it is essential to confirm meanings (Geertz, 1983, Hutchby & Wooffitt, 1998). Shared meanings were verified via a pilot test, continually back-checking meanings throughout data collection, and comparing findings to existing literature.

3.5.1 Pilot Test

The first step taken towards verifying shared meanings was to complete a pilot test of the research protocol. The faculty advisor of the Cornell Crohn's and Colitis Affiliation participated in a pilot test of the entire process that a typical informant would undertake. During this process, she assisted by determining whether instructions were clear and understandable, as well as alerting the researcher to any misunderstandings that were expressed.

3.5.2 Verification and Grounded Theory

Verification was continued throughout the research process (Morrissey, 2007). Due to the fact that Grounded Theory calls for simultaneous data collection and analysis, the researcher was able to question informants on the aptness of findings as they emerged (Milliken & Northcott, 2003). For instance, some questions were phrased in the format, "A past participant mentioned experience X, have you had a similar experience?" Additionally, meanings were verified throughout each interview. For example, questions in the format, "You mentioned that X made you feel X, is that correct?" were asked. Follow up interviews also allowed for further verification. Three of the original ten

informants were available for follow up interviews. During follow up interviews, informants were asked to verify that emerging concepts were accurate.

3.5.3 Verification and Previous Literature

Findings were also compared to previous literature for verification. The aim of the study was to discover undocumented processes, thus not every finding was previously documented. However, findings were compared to the existing literature to check for inconsistencies. Any inconsistencies that were found were pursued in greater depth. For instance, one informant mentioned that she felt that she was empowered in making healthcare decisions, but wished that she was not. This concept contrasted with literature on patient empowerment, and therefore future informants were asked more in-depth questions regarding empowerment in order to clarify the theme.

3.6 Data Analysis

Data collection and analysis were carried out in a recursive fashion. As data was collected and transcribed, it was analyzed. In turn, the analysis of the data shaped further data collection.

3.6.1 Codes, Categories, and Memos

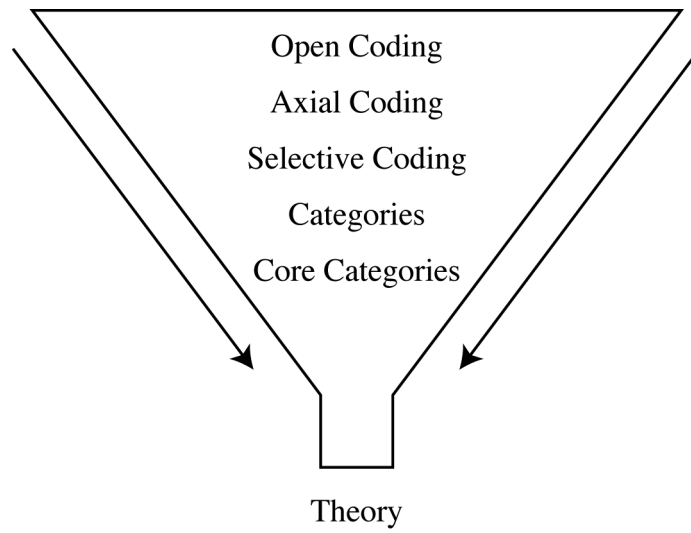
Data analysis began by coding the transcribed interview data. Open coding was initially used to identify provisional concepts (Strauss, 1987). Through open coding, approximately fifty codes total emerged from the data. Next, axial coding was used to compare concepts. Codes were compared to existing codes and to new codes that

emerged from newly collected data. Finally, selective coding was carried out in order to more deeply explore concepts and reach saturation (Draucker, 2007).

As themes began to emerge from the data, codes were clustered together to form categories. The newly formed categories captured similar phenomena between two or more codes (Strauss & Corbin, 1990). Codes within each category were examined and compared against each other, as well as against existing literature (Glaser & Strauss, 1967). Next the categories were broken down into sub-categories, in order to more clearly define emergent concepts (Charmaz, 1983, Strauss & Corbin, 1990). Categories were then compared against each other in order to find linkages and to define conceptual order among them (Strauss & Corbin, 1990). Finally, core categories were created, which encapsulated the central theme of the data (Charmaz, 1983). This process is visualized in Figure 3.1.

Throughout the process of data collection and coding, memos were written in order to interpret codes, articulate concepts, examine relationships, and explore methodological issues (Charmaz, 1983, Eaves, 2001). The memos consisted of unfiltered thoughts, which helped clarify concepts and drive further data collection. As data collection and analysis occurred, the memos were altered, commented on, and reorganized.

Figure 3.1 Visualization of Data Analysis Process



3.7 Reciprocity

As Bryman stated, a researcher should aim to form a reciprocal relationship with her informants (2008). Throughout the research process, a reciprocal relationship was developed via a variety of methods.

3.7.1 Proactive Approach

First, an attitude of empathy, versus pity was adopted. Although the informants who participated in the study had undergone many painful and difficult experiences, it was noted that it is more helpful to treat them as comrades rather than victims. Although they may feel debilitated by their illness, one aim of the study is that they feel that they are actively improving HIT system design by participating. The objectives of the study were explained to informants to assure that they understood their role in the study. Additionally, the researcher invoked conversations where she and the informants exchanged ideas on HIT system design. Several of the informants talked excitedly about ideas they had to improve HIT and responded to ideas the researcher mentioned. For instance, one informant explained, “We talk about a lot with our Crohn’s and Colitis group at Cornell; How do we, as people who founded that, how do we get the most relevant information out to people.”

3.7.2 Self-Reflection

Secondly, the photo gathering activity and interview served as self-reflexive and self-expressive experiences for some informants. For instance, as they took photographs of their health records, some noted that they become more aware of how they organize

their records. This act, in itself, helped them realize the strengths and weaknesses of their process. One informant, upon realizing she was actually quite adept at managing information, noted, “The funny thing is, when I was taking the pictures I was thinking, ‘I don’t manage my health information.’”

Partaking in the study also gave them a platform for expression. For example, participants have expressed feelings of frustration, sadness, or anger with regards to difficulties in health information management. Chronically ill patients, especially in a cohort of young adults, oftentimes do not feel comfortable expressing such feelings to their relatively healthy peers. One participant noted that it felt good to get her frustrations off of her chest during the interview.

3.7.3 Actionable Recommendations

A final aim of this study was to make the research findings as meaningful and actionable as possible. As noted earlier, patient-centered HIT system designs can immensely improve healthcare experiences and the quality of care patients receive. The population of young adult Crohn’s patients is particularly vulnerable, in terms of having their opinion heard and acted upon (James, 1983). In addition to being patients, in a world of healthcare provider-centered HIT systems, their age and inexperience in the medical world puts them in a powerless position. Because they may have trouble speaking for themselves, it is important to accurately represent their point of view. While these patients do not have the abilities or means to influence change, written research can chronicle their experiences and translate the information into an influential format. In this

way, the research can serve as a vehicle to level the playing the field in terms of power and influence (Perks & Thompson, 1998).

CHAPTER FOUR

Findings and Discussion: Human Agents

4.1 Human Agents

As noted in the introduction, as a person attempts to reach a state of situation awareness, the person's internally held schema shapes his or her perception and comprehension. Personal attributes, such as domain knowledge, experience, and stage in life shape each person's schema. The following section will describe how young adult Crohn's patients have unique attributes that shape the way they reach a state of SA in regards to their health. The attributes described will include both experiences inherent in Crohn's patients' lives, and aspects related to the lifestyles associated with young adults.

4.2 Change in Health Status

The patients in the study described several ways their health status changes as time passes, and how these changes affect the way they manage their health information. Their experiences draw attention to the fact that living with Crohn's is not simply a matter of having a health problem, finding a solution, and resolving the problem. Rather, it is a constant process and a way of life. The health status of the patient, as well as the aspects that affect their health status, are constantly changing. Due to the variable nature of the illness, patients, social supporters (parents, friends, etc.), and healthcare practitioners must constantly update their situation awareness of the patient's health status.

After recalling a story about health communication with her doctor, one informant ended the story by saying, "...and then I start the process all over again." The ongoing, cyclical nature of having a chronic illness such as Crohn's came up often in the interviews. Overall, there were three different periods that informants described:

- Flare Ups
- Periods of Remission
- Transitional Period

Informants talked about periods of "flare up" and "remission" as if they were an expected part of life. The informants did not explicitly explain what "flare up" or "remission" meant, but rather dropped the terms into conversations on other topics. For example, when asked about how he would prepare for a doctor's appointment, one informant responded, "If it's a well visit then there isn't really anything I need...but if I'm going because I'm having an issue...". Patients seemed to have different techniques for managing their illness and health information during times of remission versus during

flare ups. These comments indicate that patients' usage of HIT systems change as their health status changes. During flare ups, patients have a higher dependency on having access to timely and accurate information, as well as a higher need for tracking symptoms and treatments. During periods of remission, patients are less vigilant about tracking their status, and less dependent on health information for making decisions that affect their day-to-day life.

4.2.1 Flare Ups

Flare ups are the times when patients are consistently, actively in pain. These seem to be the most frustrating times, as well as the times when health information transfer between several providers is most necessary. One patient experiencing this period mentioned that her and her doctor are “just trying to figure out why this pain is happening...” During these periods, having the right information in a timely manner is very important. For instance, patients might need records transferred to specialists or they might need documentation for insurance approval of procedures. One informant stressed how important having the right documentation is to getting timely care. During a time when she was in terrible pain and urgently needed to contact her pain management doctor, the office staff forgot to pass the message along to him: “I think they need to focus on who they’re hiring in their office and make sure that they’re organized and write everything down ... they need to get people in there that know what they’re doing and are dedicated to the idea of helping people... forgetting to write down a reminder to the doctor could make someone’s day so much harder than it needs to be.”

4.2.2 Remission

Crohn's patients in the study generally hold an attitude of resignation towards their illness; they know that Crohn's will always be a part of their lives. One informant explained, "... it's been my whole life... it's all I've known..." Because the patients have accepted their life-long illness, they have a very grateful attitude when they are in periods of remissions. Patients in remission noted, "I've been really fortunate, I've been in remission for a really long time, so we haven't had many problems..." and "...for the most part I've been in remission... I've been very, very fortunate and lucky..." These patients seem to be extremely appreciative of the times when they feel healthy because they do not know when their symptoms will surface again. One informant mentioned that she has trouble planning vacations, because she never knows when she will have a flare up and is reluctant to book a flight and hotel room if she will not be able to go.

Patients in remission are only able to reach the first two levels of situation awareness; they are able to both perceive and comprehend their health status, however they are not able to project their health status into the future.

4.2.3 Transitional Periods

Transitional periods are those times when a patient is actively trying to decipher what is causing a new symptom. During these times, the patient is not yet experiencing a full flare up, but rather is experiencing a small issue that can be remedied by adjusting their diet or medication. Informants described transitional periods by saying, "If I'm having a weird symptom I can go through my email and see if I've had it before that [my doctor has] noticed..." and, "...if I ever have a very light issue... for whatever reason that

[medication] has worked... they put me on that for three days... unfortunately you can't manage Crohn's that way, where you're on a medication for three days and you feel better..." During transitional periods, patients are only able to reach the first level of situation awareness. They are able to perceive how they are feeling and understand that it is not their normal state, however, they cannot understand why their state has changed from normal or how the state will change in the future.

4.2.4 Diagnosis

In addition to the three periods described above, every patient experiences an initial diagnosis period. This period, between the onset of symptoms and diagnosis, holds many challenges for patients. Oftentimes, before diagnosis, Crohn's patients begin to exhibit symptoms or feel pain for extended periods of time. Unsure of the root cause of the symptoms, the patient undergoes many physical and logistic challenges. As one informant explained, "I started to get sick and I didn't really know what was going on." Due to the uncertainty of the situation, the patient consults with several healthcare practitioners, and begins to eliminate possible causes. One informant explained the process of ruling out three other illnesses before discovering that she was suffering from Crohn's. Due to this extended process, the diagnostic period is often several months long. An informant explained, "I think I started seeing [my doctor] at the end of 2003, but I wasn't actually diagnosed until 2004. It took a few months." During this process it is essential that patients and practitioners communicate clearly with one another, in order to track which symptoms are present and which illnesses have been ruled out.

In addition to the physical and logistic difficulties of this period, the patient experiences emotional distress related to the uncertainty she feels. Before the patient understands why she is experiencing symptoms, she does not have the ability to control the symptoms or predict her future health status. The patient is unable to attain even the first level of situation awareness at this point.

4.3 Illness Management

As patients gain experience with their illness, they learn to manage it better. They gain an overall understanding of the nature of their illness, which guides improved behavioral practices. Improved practices include regulating one's diet, being aware of the efficacy of different treatments, maturing, and learning to manage health information.

4.3.1 Diet Regulation

Informants emphasized the importance of regulating diet in managing Crohn's symptoms. Patients begin to learn which foods help or aggravate their Crohn's symptoms through a process of trial and error. When patients are first diagnosed, they do not consciously correlate long-term dietary habits with the symptoms they are experiencing. Although they notice that eating a certain food might have immediate consequences, they lack an awareness of how their overall dietary habits can be used to control symptoms. Throughout the years, they begin to notice patterns and adjust their diets in order to better control symptoms. Informants, who had lived with Crohn's for several years explained, "I know how to manage my diet," "I've learned how to regulate my diet," "After three years of doing this, you start to get a good sense of what foods work and what foods

don't," and "I remember when I was first getting diagnosed, I was eating a lot of things that would cause problems, and I didn't know it at the time because I didn't know that I had Crohn's and I didn't know what that meant."

Although patients assert that they have learned to regulate their diets, some pointed out that parsing out causation and correlation is a persistent problem. For instance, one informant explained that she experienced symptoms after drinking a blended coffee beverage. She said that she was not sure if the coffee, the sugar in the drink, or the caffeine caused the symptoms. An informant also noted that it was difficult to track which foods cause symptoms, because the duration between eating a food and the onset of symptoms varies. For instance, a patient might experience symptoms on Tuesday and Saturday, and assume that he ate something Tuesday and Saturday that caused the symptom. However, upon further analysis, the patient might realize that a food he ate on Monday and Friday actually caused the symptoms. Differentiating between causation and correlation improves through time, however even experienced patients can have difficult time differentiating.

4.3.2 Treatment Efficacy

Similar to diet regulation, learning which medications and treatments help is a skill that is slowly acquired through experience. Patients often experiment with several different therapies before finding a therapy that helps. Each Crohn's patient is different, and there is no one treatment that works for everyone. An informant explained the difficulties he had in his first year of experience with Crohn's, "[I] didn't know what

work[ed] for [me]. That was a big part it. Now, after having this for three years [I know what works for me].”

Additionally, finding an effective treatment can be difficult because treatments can lose their effectiveness over time. Although patients learn what therapies work through time, a therapy that has worked in the past sometimes loses effectiveness. As an informant explained, “I was on [a medication] for a very long time. It’s by infusion. I was one of the very first people to try it, and then it stopped working for me... then I had to go on a different medication.” These inconsistencies can deter the patient from tracking the effectiveness of treatments. In addition, because diet also has a great effect on symptoms, it can be difficult for even the most experienced patients to determine the cause of their symptoms and how to control them.

4.3.3 Maturation

As the patient matures, the nature of the doctor-parent-patient relationship changes, with the patient gradually taking on responsibility for their own care as they age. Several informants talked about the process of becoming more responsible and independent. One 22-year-old informant remarked, “When I first diagnosed I was 14. My mom came to my doctor appointments, and even though I was there, she was [in charge] of everything. She made the decisions as far as what [medications] I tried or didn’t try. In the last year and a half [I have begun to] choose everything, I consult her in all of my choices, but I know exactly what I’m taking. When I was little she would just say, ‘Take this, it’ll help your stomach’ and I would take it. Now I don’t take anything, I don’t do

any surgery, I don't do any procedure without weighing the pros and cons. And I ask her about everything, but I know and I'm in control of everything."

Another 18-year-old informant reflected on how he has matured since he was diagnosed at age 15; "A lot has happened since then, it's hard to believe that I was 15 when that happened, there's just such a big difference in, you know, the maturity level and overall understanding of a lot things, between being 15 and being 18... Learning how to balance your life as you get older, whether you have a disease or not, it's easier just to manage your life because you're more mature overall... It's the same thing when you have something like Crohn's... [Maturing] allows you to handle it better."

4.3.4 Health Information Management

Patients' methods for organizing health information, such as paperwork, change as they mature and gain experience. Patient in the study fell into three categories of health information management ability:

- Patients with the least experience and maturity are not very aware of their health information. During the interviews, the concept of keeping one's records had not occurred to them until asked about it. Once asked, they had to think through whether or not they did have copies of their health records. Upon considering whether they had copies, they realized that their parents had them.
- Patients in the next group feel that they should be more responsible. They have paperwork, but it is stacked in random places: stashed in the side pocket of a car, on their dining room table, or shoved in a drawer. They felt ashamed about how

they neglected to take care of their paperwork, and felt that they really should organize it.

- Patients in the final group attempt to be extremely organized. They are very sick and understand that having the right paperwork affects the quality of care they receive. They are strategic about how they organized their paperwork, yet feel very overwhelmed at the same time. While they want to be organized, the sheer quantity of paperwork, along with the fact they do not know enough about medical care to know the proper way to organize records makes them feel discouraged. One patient mentioned that she used to be organized, but had given up and did not even know where her records were at the time.

Overall, there are several obstacles to patients organizing their health information.

Participants listed the following as reasons why they do not or find it difficult to do so:

- They feel it is unnecessary to keep track of their records because there is not much information or because it is all at the doctor's office or hospital
- They feel that someone else, such as parents or practitioners, can do a better job
- They do not know how to manage their records or feel overwhelmed by the amount of information and paperwork they have to organize
- They do not have time
- They feel that they are "bad at organization"
- It has not occurred to the patient that he/she could or should keep copies of records
- They do not know how to request records
- Offices are reluctant to release records

- Offices take a long period of time to provide copies of records
- Offices charge a fee for copies of records
- Web portals do not have all of the information patients desired
- Web portals do not allow patients to re-organize or personalize information

Unfortunately, due to these obstacles, even the most experienced and mature patients interviewed did not feel that they had the ability or resources to organize their health information to a satisfactory level. The inability to organize health information reflects on the patients' inability to reach a state of situation awareness in regards to health status.

4.4 Change in Practitioner

Young adult Crohn's patients' lifestyles cause them to transition between healthcare providers somewhat often. Some contributing factors include the transition from pediatric to adult medical care, change in health insurance, and relocation.

4.4.1 Transitioning from Pediatric to Adult Care

The transition from pediatric to adult care holds many challenges for the Crohn's patient. In addition to the patient being inexperienced with managing their own healthcare, they may need to transition between healthcare providers because they have aged out of pediatric care. Informants explained that some of their practitioners, including GI specialists, only care for patients under a certain age. After a patient has reached that age, they must find an adult practitioner. One informant explained, "I had my pediatrician, but I just turned 18 last October, so she won't see me anymore. So, I don't really have a primary care doctor right." Another informant explained how it would become

increasingly important to manage his personal health records as he transitioned from pediatric to adult care, because he would no longer be under the care of the doctor he had developed a relationship throughout the past several years.

4.4.2 Change of Health Insurance

Young adult Crohn's patients may also need to change practitioners because they have recently transferred from their parents' or university's insurance plan to a personal or career-related insurance plan. An informant noted, "I didn't have a primary care doctor [when I was diagnosed] because I had just gotten off of my parents' insurance." She went on to explain that not having a primary care physician made the diagnostic period difficult because she lacked guidance. She believed that a primary care physician could have helped her decide which specialists to see, and in what order, in order to be diagnosed more quickly.

4.4.3 Relocation

Relocating also complicates the cohesion of medical care. Many patients in this age group relocate to attend college. Some of the college student informants mentioned that they have a GI specialist both in their college town and their hometown, because they travel back and forth for summer and the school year. Transitioning between doctors every few months leads to issues with cohesion, because the doctors in each city are not up-to-date on the patients health status and treatments. Some of the young professionals mentioned that they needed to change doctors when they moved for career reasons. One informant, who is currently a student, mentioned that he plans on having a career where

he will travel quite a bit. He went on to describe the increasing importance of having a set of his health records, as he anticipated needing to see different practitioners in the cities he traveled to for work.

4.5 Domain Knowledge

The patients interviewed lacked a level of domain knowledge which would be helpful in understanding their illness and organizing their health information, in order to reach a state of situation awareness. Areas where patients lack domain knowledge include healthcare protocols, understanding medical information, and determining legitimate sources of health information.

4.5.1 Healthcare Protocols

The young adult patients interviewed tend to have very little understanding of the inner workings of the medical world. The patients' assumptions about healthcare protocols often do not match reality. In turn, patients have trouble facilitating their own medical care. The misunderstanding spans both the administrative and the medical aspects of healthcare. For instance, patients noted that they do not understand administrative processes, such as: how to get referrals, how health insurance billing works, and the protocols for re-ordering medication or attaining copies of test results. Patients also mentioned that they do not understand medical protocols. For example, one informant mentioned that she does not understand why she has to wean onto and off of a medication. Another informant noted that he does not understand why his doctor orders certain blood tests.

4.5.2 Understanding Information

Informants noted that they have trouble understanding medical information that their doctor gives them. They mentioned that their doctor will often print out information about their illness or medications at appointments. However, this information was hard to understand because the information:

- Was written in technical language
- Was more geared towards scientific results than actionable guidelines, such as how to take the medication, how the illness will affect the patient and what to do about it
- Was too lengthy

The fact that information presented by the doctor is difficult to understand puts the patient in a difficult situation. The doctor tells the patient to not look at unreliable information, such as information on the Internet, and to only look at the information that he has given directly to the patient. However, the printed information is written for an audience of medical professionals and difficult for the patients to understand. So, the patient is left with the choice between information that is either unreliable or incomprehensible.

4.5.3 Legitimacy of Information Sources

The legitimacy of information sources, specifically those on the Internet, was an area of contention with many informants. They seemed to want to convey that they were “responsible” and would never read unreliable sources online. However, some would

then reference a time when they had referred to an unreliable Internet source. Informants either denied that they would read information from an unreliable source or were ashamed of admitting that they did use them. For instance, one informant said, “I would just call my doctor [if I had a question], who knows what you’re reading.” There were two very notable conversations around this topic.

In the first conversation, the informant started by saying “I don’t go on Wikipedia ... I don’t read [sources that] everyday people can put information and put their input on, I don’t read those...” followed by, “[My mom] is on every Crohn’s board online that she can think of...” and “I know it sounds silly, because anyone can put anything on the Internet, but whenever I get a new medication, I go online... and read everything that there is possibly out there to know... all the side effects and everything...” This indicates that although a patient might know that a source is less than legitimate, their need for information outweighs the risk of reading false information. This also conveys a need for a larger quantity and more accessible legitimate information. Patients seem to internally struggle over wanting to be “good” and only read information that their doctor gives them, while at the same time thirsting for more information on things that greatly affect their lives.

The second conversation consisted of an informant assessing her judgment of what constitutes a reliable information source as she was being interviewed. First the informant asserted that she does not visit any unreliable websites; she only visits WebMD to attain health information. However, when questioned why she thought WebMD was reliable, she couldn’t explain and began to question her own judgment:

Informant: You can just tell if [a website is] reliable... I know WebMD is a good one, but that's basically it.

Interviewer: What makes you feel that WebMD is a reliable website?

Informant: Um... I'm not sure... I just feel like it's trustworthy... um... I mean... it's big and it's well known and they have magazines and stuff like that... and it's like run by doctors... I'm not really sure if it's run by doctors... it's actually not good now that I'm thinking about it... I don't know if I trust WebMD... now that I'm thinking about it... uh oh.

Informant also talked quite a bit about how to make the right kind of information easily accessible. One informant, in particular, talked a lot about the time and effort he put into finding reliable sources, and reading and trying to understand the information he found. He wishes that a central website containing this type of information existed, and that the website not only curated the information, but updated it with the most recent research and made it easy for anyone to understand.

CHAPTER FIVE

Findings and Discussion: Transactions

5.1 Patient-Practitioner Transactions

Transactions between patients and healthcare practitioners are of utmost importance because they allow both patients and practitioners to increase their level of situation awareness. The patient increases the practitioner's SA, in that the patient better understands what symptoms are currently occurring, and which diet and treatment options are currently being used. The practitioner increases the patient's SA, in that the practitioner has a higher level of domain knowledge, and can therefore put the patient's experiences into context and project the patient's future health status.

5.1.1 Communication at Office Visits

Informants described office visits as the main junction of information sharing between doctors and patients. As described by the informants, office visits consistently follow a sequence of steps. First, the doctor asks a standard set of questions in order to establish the patient's status. For instance, one informant explained, "Before I even get into the story of recounting what's going on [my doctor] will ask certain questions, as far as [my] appetite and things like that." Informants also mentioned that their doctors review a list of symptoms and ask if they had experienced any since the last visit. The patient then explains any experiences or concerns that have come up since the last visit. One informant explained that she always brings a list of concerns that she would like to talk about at the appointment. She stated, "When I get there, [my doctor] asks me how I'm feeling and waits for me to pull out my piece of paper... I ask the questions and we go through them one by one." Next, the doctor examines the patient. For instance, one informant noted that after they discuss her symptoms, her doctor listens to her stomach with a stethoscope. The final step consists of creating a treatment plan and follow up steps. As noted by an informant, "...He gave us... options, he gave us treatment ideas: 'This is what we're going to do first, second, third. If that doesn't work, we're going to try this...'" Another informant recounted, "At the end of the visit [my doctor] would say, 'Go to the front, make an appointment for six weeks.' And I would usually have to get a blood test, so he would write me a prescription for that."

The office visit procedure described by informants had an interesting overlap with the SOAP (Subjective, Objective, Assessment, Plan) Method (Reznich, Wagner, & Noel, 2010). The SOAP Method is a four-step process employed by healthcare practitioners during appointments (Reznich et al., 2010). The four steps include:

1. Subjective: Collecting the patient's signs and symptoms
2. Objective: Carrying out a physical examination, looking at the results of laboratory tests
3. Assessment: Completing a differential diagnosis, looking at history, physical examination, and test results within systematic frameworks
4. Plan: Planning to collect further data for a diagnosis, making suggestions for therapeutics and management (Reznich, et al., 2010)

In addition to serving as a method for organizing the office visit, the SOAP Method also helps practitioners organize data: "Doctors have used the subjective-objective-assessment-plan (SOAP) note format to [organize] data about patient problems and create plans to address each of them." (Reznich, et al., 2010). In this way, the SOAP Method forms both the process and products of office visits.

Interestingly, informant recollections correspond with three out of the four steps in the SOAP Method. Informants described steps one, two, and four (subjective data collection, objective data collection, and planning, respectively), but failed to mention step three (assessment by means of differential diagnosis). This discrepancy implies that patients and practitioners carry out different processes that each other are unaware of while they synchronously communicate.

Every participant mentioned that their doctor takes notes in some format during the office visits. Many patients and parents also write down notes at office visits. Patients and parents also bring notes, including lists of recent symptoms and concerns they would like to discuss. Additionally, the doctor brings notes as well, in the form of test results, records, surveys, etc. The office visit serves as the major transaction where each agent

brings information, exchanges information with other agents, adjusts their SA based on the new information, and records the newly acquired information.

5.1.2 Remote Communication with Practitioners

Participants described most remote communication with healthcare professionals occurring by phone. Many informants mentioned that they have their GI doctors' numbers and feel comfortable calling at any time. Many participants said they have a close relationship with their doctor, and said that their doctor allowed them to call the doctor's personal phone on evenings and weekends if they needed to.

Participants also mentioned that they contact their doctor's office immediately if they are experiencing a symptom. For those situations where the patient does not have the doctor's cell phone number, they said that they usually call the doctor's office and talk to the staff, who then take a note, and have the doctor return the patient's phone call.

Most of the participants have called their doctor's office and feel comfortable doing so. One patient did mention that the office staff at one of her doctor's offices does not treat her with as much respect as they do to her mom, because she sounds like she is young. To avoid this problem, her mom calls the office when she urgently needs something. Another patient mentioned that her mom always calls the office for her.

Patients mentioned communicating with their doctor via the Internet in a limited fashion. One informant explained that her doctor's assistant emails her notes after each office visit. She noted that these are helpful to have, however, she does not email her doctor directly. Another informant explained that she has emailed her doctor via a secure medical web portal. However, she stopped using this form of communication because she

did not know if her doctor had received her messages, nor did her doctor respond to the messages.

5.1.3 Relationship with Practitioners

Crohn's patients that were interviewed tend to have close relationships with their healthcare providers. This may be a sampling error; one of the participants mentioned that his GI doctor is a close family friend. Other informants noted that they have parents who work in the same hospital with their GI doctors. These personal relationships might be the reason their relationships are so close. However, even those who do not have a personal connection with their doctor mentioned that they had strong relationships with their practitioners.

One participant explained that she is extremely sick. Recently, she has spent the majority of her time in the hospital. Although she has no other personal connection to her doctor and has only been seeing him for three years, they have a very close relationship. She describes him as "awesome," mentioned that he got very upset when another doctor she was seeing did not file her paperwork correctly, gave her his cell phone number and says to call at any time, and she noted that he explains things very calmly to her because he knows she has anxiety related to her condition.

In addition to this close relationship with her GI doctor, this patient mentioned relationships with nurses and other hospital staff. She was in and out of the hospital for nine months straight, leading the hospital staff to become familiar with her condition. Because of her unstable condition, she often has to go to the ER for pain medication and treatment. During her trips to the ER, she has to be treated with an unusually high level of

medication. Unfortunately, she cannot always go to the ER at the hospital where the staff are familiar with her condition. When she visits other emergency rooms, the staff is not familiar with her extremely high dosage of medication, which causes suspicion from hospital staff. Therefore trips to her usual ER are much less stressful for her. When asked if she could simply bring discharge papers from prior visits, she said that she has done so, but it is more effective to simply have her doctor's number on hand and have him speak directly to the hospital staff.

These close relationships are an important factor in the entire system maintaining a high level of distributed situation awareness. The closer the relationships between human agents in the system, the more aware each agent is of the other agents' information needs. This allows all agents to more effectively communicate with each other.

5.2 Patient-Patient Transactions

In addition to parents helping, informants mentioned other people, such as other patients, helping them. Patients seek social support and are resourceful in finding alternative channels to get information.

As mentioned above, the information that patients receive from doctors does not entirely fit their needs. Patients communicate with other patients in many formats in order to get the information they need. For example, patients mentioned:

- Using online message boards
- Talking to friends with the same illness
- Reading blogs of other patients

- Talking to people in Crohn's and Colitis groups on campus
- Talking to other patients at a camp especially for Crohn's patients

For the most part, patients feel very positive about communicating with other patients.

Although they do not use other patients' experiences as the first the source of information in decision-making, the information does help them in many ways. Firstly, this type of communication alleviated many of the downfalls inherent in technical medical information. Secondly, it helps give patients a basis for comparison. Many of the informants wonder:

- Whether they chose the right treatment or doctor
- How taking a new medication will impact their lives
- How other patients cope with having Crohn's
- How "bad" their Crohn's is in relation to other patients
- Which non-traditional treatments other patients have tried
- What surgeries other patients had and how the healing process was
- Which foods help or hurt other patients
- How other patients dealt with the social aspects of having Crohn's (e.g. embarrassing trips to the bathroom, taking medication in public, and not being able to eat things their peers can eat)

One informant explained how reading about other patients' experiences with certain medications helps her decide if she will take the medication. Although this informant noted that she always reads literature about the medication that has been given to her by her doctor, she feels that other patients' first-hand accounts of their experiences with the medication give her a better sense of what it would be like to take the medicine.

Overall, comparing with other patients serves as a good way for patients to feel less alone and unguided in their illness. However, while communicating directly with other patients can provide patients with helpful information, it can also provide biased information. Informants noted that people usually only write or talk about extreme experiences, so a patient reading a message board may only see the very good and very bad reactions. Some informants mentioned that online message boards have been a hindrance. The fact that worst-case scenarios are commonly written about added to the anxiety that they felt about their illness. One informant mentioned that she has had to stop herself from looking things up on the boards. While she likes them because they provide quickly accessible information, they also increase her Crohn's-related anxiety.

Additionally, while the person writing the account might think that they're giving an accurate description, they might not be. For instance, a patient might think they had a bad reaction to medication, while it was actually a reaction to a new food that they tried. While scientific information is impersonal and less understandable it takes these factors into account.

5.3 Practitioner-Practitioner Transactions

Informants described a wide range of experiences with practitioners communicating with each other. Some said that they communicate well, while others said they communicate terribly.

For those who communicate well, the process of transferring information, such as records or orders, is a seamless process. One participant described going to an infusion center to get a medication infusion. He said that the infusion center already had his order

ready to go, in their computer system, without him needing to do anything. He also mentioned that documents have traveled easily between the hospital and his doctor's office. This participant wondered if the communication went smoothly because the doctor had worked for years at the same medical center that the infusion center and hospital are located in. He also worries that information will not travel as easily if he needs to go to the hospital near his college, which is in a different state than his GI doctor.

The idea of doctors in the same group or location communicating better with each other was also evident when a participant told me that two of his doctors work well together, while his nutritionist does not communicate at all with the other two. Instead of the nutritionist speaking directly with the patient's other practitioners, the patient simply emails or tells her in person at an appointment, how he is progressing. Patients who are burdened with the responsibility of transferring information between doctors felt uncomfortable doing so because they were unsure of what information to tell each doctor and how to explain the information.

Crohn's patients mentioned that they need to see a slew of specialists, which may be in different medical groups, or be disparately located. This puts a lot of the burden of communication on the patient, rather than medical professionals. In this case, the patients are unclear of whose responsibility is it to coordinate the patient's care among these practitioners. They felt that this responsibility was given to them, and that they did not feel adequately experienced to handle such a responsibility. Because the patients are put in this position, the DSA of the entire system suffers. Not only are all agents not attaining the information they need, but they are also often unaware of the information needs of

other agents. Additionally, practitioners may be unaware of vital information that may have been lost in the transaction from practitioner to patient to practitioner.

CHAPTER SIX

Conclusion

6.1 Design Recommendations

The findings described in Chapters 4 and 5 provide a base of knowledge with which to better understand how young adult Crohn's patients organize and communicate health information. This knowledge can be applied to the design of HIT systems, in order to improve the utility they serve to this population. Recommendations for HIT systems designed for young adult Crohn's patients are described below. They include symptom; diet; and treatment tracking, the usage centralized HIT systems, providing an administrative tracking function, providing patients with actionable information, providing information that is appropriate for the patient's life stage, allowing for remote

communication with doctors via the development of remote billing codes, and providing a platform for social support.

6.1.1 Symptom, Diet, and Treatment Tracking

The findings of this study have shown that tracking symptoms can be difficult to Crohn's patients for several reasons. These reasons include the unstable nature of Crohn's Disease, including phases of diagnosis, flare up, transition, and remission. Additionally, both diet and medical intervention can affect the state of Crohn's symptoms. Diet and medical interventions often affect the patient's health status long after they have been implemented and can also lose potency over time. Due to the combination of these aspects, it can become difficult for patients to accurately track factors that alleviate or aggravate their symptoms.

Health information technology can mediate the aforementioned problems by providing symptom, diet, and intervention tracking technology. Several informants explained that they track the above components in a number of ways. For instance, one informant described using the combination of a mobile dieting app and a journal to track her food intake and symptoms, respectively. Other informants explained that they wrote down their dietary intake, medication, and symptoms in a diary. Some informants disclosed that they simply remembered what helped or irritated their symptoms.

In all cases, the patients noted that while these methods were somewhat helpful, the distinction between causation and correlation was difficult to make. While it can be difficult for people, and in particular novices, to recognize patterns and establish causality, software can easily do so. For instance, IBM has recently developed analytic

software that can extract relationships, determine trends and patterns, and pinpoint anomalies in healthcare data (Medical Informatics, 2012). The author suggests that similar software be used in applications specifically developed for Crohn's patients. In such applications, patients will have the ability to input diet, medical intervention, and symptomatic information. The application will continuously analyze the patient's personal data to determine patterns over time.

Additionally, the application will aggregate anonymized data from subsets of users in order to discern patterns within the larger group. The output of the analysis will not only include data that will help patients determine which diet and treatments to implement, but also help with planning. As noted earlier, Crohn's patients often have difficulty planning life events, such as weddings or vacations, because they cannot predict when they will experience a flare up. The information provided by the application will help inform the patient of the likelihood of a flare up occurring. This information increases the patient's potential for SA in the second two stages of Endsley's Model. The patient is able to better comprehend the meaning of information and predict the status of his or her body in the near future.

6.1.2 Centralized HIT Systems

The ever-changing quality of Crohn's disease, mentioned above, poses a challenge to patients and healthcare providers alike. Additionally, experiences inherent to the young-adult lifestyle produce further variables which induce inconsistencies in patient care. As mentioned in Chapter 4, patients in this age group tend to change healthcare practitioner often due to the transition from pediatric to adult care, changes in health

insurance, and relocation. Crohn's patients also see many practitioners, ranging from gastrointestinal specialists to pain-management doctors, which furthers the incongruence of their healthcare regimens. These challenges can be partially ameliorated by keeping clear lines of communication between practitioners, however it is a notably difficult for practitioners in disparate locations to do so.

One aspect related to this challenge is the diversity of information technology systems used by each medical facility, and the lack of interoperability between systems. As noted in the interviews, healthcare facilities often lack the capability to access electronic records from other facilities and reach administrative roadblocks in transferring hard copies of patient data.

Patients interviewed have a strong desire to control their own information. Several informants expressed interest in electronic health records that could be accessed by the patient and shared with the team of practitioners. Shareable records will help keep all doctors on the same page and aware of changes to the patient's health status. Unfortunately, technological and privacy issues have deterred this concept from becoming a reality. In the meantime, the patient must cart paper records from doctor to doctor, which is often inhibited by lost files and administrative hindrances. Patients, whose medical files are too lengthy and complex or too incomplete, are often asked by practitioners to verbally recall their medical histories.

A central HIT system, that facilitates sharing between providers and is Internet accessible to patients, is instrumental in alleviating these frustrations and providing better care to this vulnerable population of patients. In using such a system, all providers will be able to easily access records, without having to ask questions or wait for records to arrive

from other providers. This will improve healthcare by assuring that the records a physician reads are complete and correct, thus allowing physicians to make more informed decisions and reduce errors. Additionally, this will increase the productivity of office visits. Instead of spending several minutes relaying a health history, patients can simply focus on discussing current issues with their doctors.

HIT systems may also borrow from the traditional transition note, a short passage written by a physician, that relays an overview of a patient's health history (Osterlund et al., 2005). Including a transition note module in an HIT system, will allow doctors to communicate the most relevant information in a brief format. Furthermore, linking key words or phrases in the transition note to the full record containing relevant information, will increase the ease and speed with which doctors can access targeted information.

6.1.3 Administrative Tracking

As mentioned earlier, patients have trouble organizing health-related paperwork due to obstacles in healthcare administration, combined with the patients' unfamiliarity with administrative protocols. In turn, even the most experienced patients lack the ability and resources needed in order to organize their health information to a satisfactory level.

Providing an administrative tracking tool in health information system design can mitigate the current issues. A tracking tool will provide patients with information about the administrative aspects of their healthcare in real time.

Let us look at an example of how a tracking tool might improve a particularly frustrating process. An informant described a recent chain of events that occurred while trying to obtain a refill on a prescription:

- Step 1: The patient left a voicemail for his doctor, explaining that he had run out of his medication.
- Step 2: The doctor received the message at a later time and called in a prescription to his pharmacy. In the meantime, the patient was not aware of whether the doctor has received his message or whether the order for the prescription had been placed.
- Step 3: The patient eventually received a call from the pharmacy, alerting him that the prescription was ready.
- Step 4: The patient went to the pharmacy to pick up the prescription, only to find that his new insurance did not cover his prescription.
- Step 5: The pharmacist verified that a different, yet similar prescription that was covered by his insurance could be substituted. However, the pharmacist was required to speak with the patient's doctor to obtain a new prescription for the alternate medication.
- Step 6: The patient decided to go home, and returned to the pharmacy the following day, causing him to miss a dose of his medication.

Some aspects of this situation could have been avoided with behavioral changes from the patient. For instance, a more experienced patient might have spoken with his doctor at an appointment before his medication ran out. An experienced patient might have also called the pharmacy ahead of time to assure that his medication would be covered by his new insurance. However, not all patients are experienced patients and not all patients are aware of the administrative roadblocks that may occur.

Now let us examine the same situation, where the patient is equipped with an electronic medical record that has an administrative tracking tool:

- Step 1: The patient receives an email alert a week before his prescription runs out.
The patient clicks a link in the email alert in order to re-order his medication.
After re-ordering, the patient is able to log into his electronic health record at any point, in order to view an updated status of his order.
- Step 2: The doctor receives an automated message that the patient requires a refill.
The automated message contains an alert regarding the patient's change in health insurance.
- Step 3: The doctor orders the refill via an ordering system that is integrated into the patient's EMR. At this point, the patient can see that the status of his order has changed. He is able to see what prescription was filled and which pharmacy it was filled at. He is also able to cancel or transfer the prescription within his personal EMR.
- Step 4: An automated message is sent to the patient when the prescription has been filled. The status of his order is also updated in his EMR. The message sent to the patient contains actionable directions. For instance, the message might say, "Your prescription for [medication] has been filled by [pharmacy] at [address]. Your out-of-pocket expense for this medication is [amount]. Please pick up your prescription by [date]." Using this information, the patient knows exactly what steps he needs to take to retrieve his medication.
- Step 5: The patients receives his medication on time and without incident.

Administrative tracking is a way to keep all human agents on the same page. Communication regarding the steps each person needs to take are clear and transparent. The patient is never left wondering if administrative tasks related to his health have been completed. An administrative tracking system will be helpful not only in refilling prescriptions, but also in a plethora of situations, such as transferring medical records or receiving insurance approval. A related example, the contact order tracking tool on 1800Contacts.com is shown in Figure 6.1. This tool allows patients to see the status of contacts they have ordered, including whether the prescription has been verified and whether the contacts have been shipped.

Figure 6.1 Administrative Tracking Example

[Dashboard](#)
[Order Status & History](#)
[Shipping & Billing Info](#)
[Account Settings & Password](#)

Order Status

Status for order number 123456789 received on 12/15/2012

Great news! Your order has been shipped. [Get the tracking number here](#)

Order Placed

Verifying Lens Availability

Verifying Rx with Doctor

Printing Order Label

Packaging Your Order

Shipped!

History

Order Number	Date Ordered	Patient Name
123456789	12/15/2012	John Doe

[Hide Details](#)

Order Summary

[Print this receipt](#) [Email this receipt](#)

Order Date:

Order Status:

Order Number:

Customer Number:

Shipping Time:

Billing:

Shipping:

Products:

Subtotal:

Standard (5-7 business days) FREE

Tax:

Top 4 reasons people love us:

Free Shipping
over \$50

20/20 Guarantee

Authorized Retailer

Safe Shopping

(Contact Lenses, 2012)

6.1.4 Actionable Information

As noted in the Findings section, patients often find health information both difficult to understand, as well as to act upon. Patients often have difficulty understanding medical information because it is written for an audience of medical professionals. For instance, a patient might read a lab report that shows the results of a blood test. While the report provides reliable information, the results are ultimately meaningless to the patient, because the patient may have trouble deciphering what the results mean in the context of his or her life. Upon further inspection of the report, the patient might notice that a certain level is out of the normal range. However, the utility of this information is limited, because the patient has a narrow frame of reference of what a normal level is and what being outside of that range means. While some patients turn to friends or relatives who can decipher the meanings of the report, others turn to fellow Crohn's patients. Patients might ask another patient about his health status while he had similar levels, in order to gauge the implications of the lab report.

The author proposes providing patients with information that is actionable, in addition to being informative. For example, a lab report that shows a patient's blood levels allows a patient to only reach Endsley's first level of SA. A lab report with actionable information allows the patient to reach the second and third levels of SA. Consider a lab report with the following text, "Your [blood level] is [number]. This is outside of the normal range and higher than [number] percent of Crohn's patients. Your doctor has prescribed [medication] in order to restore you to a normal level. Take the prescription as directed and schedule an appointment with [doctor] to follow up on your

health status [time period] from today.” Using this information, the patient can comprehend what the information means and use the information to plan future events.

6.1.5 Life Stage Appropriate Information Formats

Younger patients might not yet understand the consequences of their medical decisions and actions. They might also be used to their parents providing them with short-term consequences, in order to motivate actions that have long-term effects. For example, a mother might motivate her son to take his medication by creating a medication check off chart. The son might not have yet experienced the physical importance of taking the medicine, but rather knows that he must because his mother tells him it is important.

The results of this, as De Nooijer et al. point out, is that younger patients tend to be less internally motivated to actively participate in healthful behaviors (2005). HIT systems that are geared towards a younger demographic can help engage and motivate younger patients to actively participate in their healthcare. In conducting a review of the literature on digital health interventions aimed at young patients, Crutzen et al. identified aspects of successful intervention delivery, including customization of content and social support (2011). Combined, these interventions may be helpful in motivating positive healthcare behaviors.

Customized content in an HIT system may help younger patients both understand information better and feel more control over their health. Content in an HIT system should be targeted to the end user (Crutzen et al., 2011). As noted by Crutzen et al., HIT systems should be “tailored to the social and developmental preferences of adolescents

and designed to be age relevant, fun, and participatory—capturing adolescent attention while allowing individual control over the pace of learning.” (p. 54, 2011, Long, Armstrong, Amos, Shriver, Roman-Shriver, Feng, & Blevins, 2006).

Barak & Fisher suggest creating systems with information provided in both text and graphical format, and with a high level of interactivity (2003). Ways with which to achieve this include providing interactive progress charts, incentives, instructional videos, interactive games, downloadable charts to plan activities, quizzes with instant feedback, age-appropriate virtual settings, and by placing healthcare concerns within a social context (Crutzen et al., 2011). For example, an HIT system might have a special login portal for younger patients. This portal can be designed similarly to other websites that are popular with young patients, in order to keep their attention and make them feel more comfortable.

6.1.6 Remote Communication Billing Codes

Several informants noted that they communicate remotely with their practitioner. For the most part, informants communicated by telephone, while there was limited communication via the Internet. Informants noted that they would appreciate the opportunity for remote and asynchronous communication with their doctor. Due to the fact that issues can occur at unpredictable times, patients would like to be able to communicate their issues outside of office hours. Additionally, patients noted that it is not always convenient to talk to their physician at the time he or she calls. Informants also noted that written, remote communication is helpful, because it allows the patient to have a transcript of the conversation, which they can refer to at a later time. Convenience

is another benefit of remote communication; not all issues require an office visit. The ability for a patient and practitioner to have a quick information exchange would streamline the treatment process.

A web portal that allows patients to email their practitioners will fulfill the above requirements. Unfortunately, it is currently difficult for practitioners to communicate this way due to the lack of a billing system (Lehmann et al., 2008). Practitioners currently do not have a means to bill insurance companies and be reimbursed for the time they spend answering emails or consulting with patients over the phone (Lehmann et al., 2008). However, professional societies, such as the American Academy of Pediatrics, are currently developing health insurance billing codes for “Non-Face-to-Face Care” to address this issue (Lehmann et al., 2008).

6.1.7 Social Support

According to Crutzen et al. (2011) social support can be essential in keeping younger patients engaged in their healthcare. This sentiment was echoed by informants. Informants mentioned obtaining peer support through various means. These included web-based formats, such as blogs and message boards, in-person conversations, and attending events targeted to Crohn’s patients.

While informants noted that online social engagement tools, such as message boards and blogs allowed them to communicate with other patients, they felt hesitant to trust the information obtained through such means. They felt that information found on such sites contained only worst-case-scenario stories, rather than balanced accounts of illness. They also wondered whether the information found on these sites was reliable.

On a good note, informants liked that they found other people that they could relate to and share advice and stories with.

An HIT system that provided patients with doctor-curated patient profiles will ameliorate the above issues. The patient profiles will provide patients with reliable, yet relatable information. The profiles will contain stories told from the patients perspective, but edited by a health professional to assure accuracy of information. In addition the profiles will focus on providing patients with balanced accounts of illness. For instance, stories of patients at different stages of illness and with different health outcomes might be included. Additionally, personal details, such as the patients hobbies and photographs of the patients may be included in the profiles. This would allow for patients to feel a connection to one another.

6.2 Limitations and Future Research

6.2.1 *Limitations of Theory*

The Distributed Situation Awareness theory described in Chapter 2 provided an appropriate framework with which to examine the complexities of information-sharing between Crohn's patients and healthcare providers, as part of a larger socio-technical system. In this study both Endsley's three-step SA model and Smith and Hancock's perceptual cycle model were used. The combination of these two models allowed the researcher to examine the intricacies of how patients reach a state of SA, as well as how they maintain a state of SA over time. This combination places an emphasis on changes over time and the trajectory of events. It may be advantageous to use a combination of both Endsley's and Smith and Hancocks models in future research, when examining

Crohn's Disease-related SA, due to the unpredictable nature of the disease and the changes that patients experience as they age.

6.2.2 Limitations of Research Methods

As noted in Chapter 3, there are some limitations inherent in the research methods used in this study. While the somewhat homogenous group of informants provided rich data to describe the experiences of a targeted population, the findings may or may not be generalizable to other populations. For instance, much older, younger, less educated, or less compliant patients may have vastly different practices. Another limitation of this study is the short time period in which it was undertaken. A longer, longitudinal study may more adequately capture how the practices that patients undertake evolve over time. Additionally, the study was limited in that the research was completed in a laboratory setting. Although photos were used to acquaint the researcher with the informants' usual environment, research involving observation would add to the depth of information collected.

6.2.3 Future Research

This study served as a formative exploration of health information and communication practices of young adult patients with Crohn's Disease. Further evaluation of findings set forth in this report would be advantageous to the academic and medical communities. For instance, a survey could be administered in order to further verify findings. Additionally, further qualitative research with a larger or more diverse group of informants would increase the depth and richness of findings. Furthermore, it

would be auspicious to prepare mock-ups of the design recommendations described above, in order to conduct usability testing. Through this and related studies, it has become apparent that future research and design implementation are both desirable and necessary in the health information technology domain. With adequate research and application, health information technology has the capacity to change the lives of Crohn's patients for the better.

APPENDICES

Appendix A: Informed Consent Form

Consent to Participate in a Research Study:

Designing Health Information Technology Systems that Work: A Study of Young Adults with Crohn's Disease

Principal Investigator:

Erica Bupp, graduate student, Department of Design and Environmental Analysis, Cornell University

You are invited to be a part of a research study titled "Designing Health Information Technology Systems that Work: A Study of Young Adults with Crohn's Disease." The purpose of our study is to understand the ways in which young adults with Crohn's disease use health information to manage their health. The study will have implications for the design of future health information technology (HIT) systems.

We are asking you to participate because you are young adult (age 18-29), who is currently suffering from Crohn's Disease.

If you agree to be part of the research study, you may be asked to participate in an image-gathering exercise and two (2) interviews, either by phone, video chat, or in person. Interview topics will include questions about how you manage your health information. Questions regarding the content of the health information will not be asked. We may contact you again during the next six months with additional questions and/or for one or more follow-up interviews. Each interview should take between thirty minutes and one hour. All participation is voluntary, and you are free to decide whether to participate further whenever you are contacted again. You may also choose to participate in some parts of the study (e.g. interview) and not others (e.g. image-gathering). You may choose to leave the study at any time without any negative consequence.

To ensure that our conversations are recorded accurately, we would like to make an audio recording of the interview. We will also ask that you participate in an image-gathering exercise, where you will capture photographs and screen shots, documenting your information management process. You will have the opportunity to edit and censor images before the researcher views them. You may decline to provide images or be audio recorded and still participate in other parts of the study.

A pseudonym will be used in our notes and multimedia records. When study results are released, we will remove identifying information from the data by omitting or aggregating data about relationships, gender, location, etc. However, there is still a possibility that someone may observe or deduce your participation in the study, or they may be able to guess your identity in one of our research publications despite our best efforts to conceal it.

The researchers plan to keep all study data, including our notes and all images and audio recordings, along with identifying information, indefinitely in a secure, password-protected digital repository for future research.

There are occasional reasons why people other than the researchers may need to see information you provided. This includes organizations responsible for making sure the research is done safely and properly, such as Cornell University's Institutional Review Board.

You will be asked question about how you manage health information. Although you will not be asked questions directly relating to your health, you may feel that the questions asked probe for personal or sensitive information. If you feel uncomfortable answering any question, you may decline to answer.

Participation in this study may be directly beneficial to you, in that it may provide you with a self-reflective and/or expressive experience. Your participation may also contribute to society and/or academic knowledge by providing implications for future HIT system designs.

As compensation you will receive a \$50 gift card upon completion of the image-gathering exercise and two (2) interviews.

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Page 1 of 2

If you have any questions about your rights as a research participant, please contact the Cornell University Institutional Review Board, (607) 255-6182, East Hill Office Building, 395 Pine Tree Road, Suite 320, Cornell University, Ithaca, New York 14850, ma354@cornell.edu.

By signing this document, you are agreeing to be part of the study. Participating in this research is completely voluntary. Even if you decide to participate now, you may change your mind and stop at any time. You do not need to provide a reason for your decision. If you choose to withdraw from the study, you may request that all data associated with you be erased. You will be given a copy of this document for your records and one copy will be kept permanently with the study records. Before you sign, please be sure that any questions you have about the study have been answered and that you understand what you are being asked to do. You may contact the researcher if you think of a question later.

I agree to participate in the study.

_____	_____	_____
Name	Signature	Date

I agree to be audio-recorded as part of the study.

_____	_____	_____
Name	Signature	Date

_____	<i>I agree to provide photographs and screen shots as part of the study. No photographs or screen shots may be used in publications or presentations without my express consent, secured separately from this consent form.</i>
Initials	

_____	<i>I agree to be contacted again in future about this study.</i>
Initials	

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Page 2 of 2

Appendix B: Initial Interview Outline

Designing Health Information Technology Systems that Work: A Study of Young Adults with Crohn's Disease

Interview Outline

Stages of Situation Awareness Formation

- Perception of Health Information
 - Monitoring
 - Cue Detection and Recognition
 - Situational Elements (objects, systematic elements, events, people, environmental factors)
 - Objects Used (paper charts, lab reports, digital systems, etc.)
 - Current States (conditions, locations, actions)
 - Sample Question: "You photographed a thick folder, full of health information; How do you use this folder?"
- Comprehension of Health Information
 - Pattern Recognition
 - Interpretation
 - Evaluation
 - Sensemaking
 - Development of comprehensive understanding of situation
 - Sample Question: "I see that you receive health information from a number of different sources; how do you integrate information from these sources to gain an understanding of your health status?"
- Projection of Health Information
 - Status of Situation
 - Dynamics of Situation
 - Extrapolation to Future State
 - Sample Question: "Do you feel the understanding of your current health status is adequate in order to make decisions regarding your health?"

Interview Outline

Domains of Situation Awareness

- Attentional Demand
 - Instability of Situation (likeliness of situation to suddenly change)
 - Variability of Situation (number of variables requiring attention)
 - Complexity of Situation
 - *Sample Question: "How often do you receive new information regarding your health?"*
- Attentional Supply
 - Arousal (how ready one is for activity)
 - Spare Mental Capacity (mental availability for new variables)
 - Concentration
 - Division of Attention
 - *Sample Question: "Do you feel that you have enough time to devote to understanding your health information?"*
- Understanding
 - Information Quantity (knowledge perceived and understood)
 - Information Quality (value of knowledge perceived and understood)
 - Familiarity (experience with situation)
 - *Sample Question: "Has any specific format (e.g. written reports, verbal directions, visual graphs, etc.) of information made understanding your health information easier?"*

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